



NPCR Education and Training Series (NETS)

Module 11: Uses of Facility and Central Cancer Registry Data

Part 2: Uses of Central Cancer Registry Data

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This presentation is Part 2 of Uses of Facility and Central Cancer Registry Data and discusses the uses of central cancer registry (CCR) data.

In the United States, cancer registry data is collected primarily in two ways: in facility-based cancer registries and in central cancer registries. These registry settings have similar methods of operation, but different goals. Also, central cancer registries can be of several different types. In this presentation, we will discuss the different types of central cancer registries and how they use their data.

Why Cancer Data is Collected in Central Cancer Registries (CCRs)

◆ Cancer surveillance

- Assess patterns in cancer occurrence
- Detect trends within populations
- Assess impact of cancer prevention programs
- Allow rational allocation of limited cancer resources

◆ Results of cancer surveillance

- Reduction of mortality from cancer
- Development of strategies for prevention of new cancer cases

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When the uses of central cancer registry data are discussed, it is first important to understand why they collect data.

Data collection by central cancer registries is also referred to as cancer surveillance. Cancer surveillance enables public health professionals to understand and address the cancer burden. Cancer surveillance assesses patterns in the occurrence of cancer, detects important trends within populations, assesses the impact of cancer prevention programs, and allows the rational allocation of limited resources for cancer.

Cancer surveillance activities have resulted in the development of effective strategies for the reduction of mortality from cancer, and strategies for prevention of new cases that include behavioral and environmental changes for some cancer types.

Types of Central Cancer Registries

◆ General CCRs

● Structure

- Governmental health agency
- University
- Combinations



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There are several types of central cancer registries, based on their organizational structure and goals. The first one we will discuss is the general type. This is the most common type of central cancer registry.

General-type central cancer registries collect data on all cancer cases within a defined population. Some are located within a governmental agency, such as a state or national health department. Some are associated with universities. For example, the Kansas Cancer Registry is located at the University of Kansas School of Medicine, which is designated by the Kansas Department of Health to operate the state-wide central cancer registry. Some are managed by a combination of agencies, such as a university acting as a contractor of the state health department. There are several examples of this type:

- (1) The Missouri Health Department, which contracts with the University of Missouri for all central cancer registry operations
- (2) The Florida Cancer Data System, which is contracted by the Florida Department of Health to the University of Miami
- (3) The Nebraska Cancer Registry, where all administrative and reporting activities are conducted by the state health department, and only the data collection activities are contracted to the Nebraska Medical Association. Some contract all or part of the central cancer registry activities to commercial organizations, such as ORC Macro International.

Types of Central Cancer Registries

◆ General CCRs (continued)

● Goals

- Determining cancer rates and trends
- Cancer control
 - Targeting populations
 - Evaluating programs
- Research
 - Epidemiologic research
 - Etiology of cancer
 - Efficacy of treatment
 - Patterns of Care studies



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- General-type central cancer registries usually have multiple goals, with the primary goal of determining cancer incidence rates and trends.
- Cancer control and prevention strategies can be guided by determining the burden of cancer at the state, regional, and national levels.
- Analysis of central cancer registry data can assist in the planning and implementation of new cancer prevention and control initiatives.
- Central cancer registry data can contribute to the understanding of cancer risks, and the need for scientific and cancer-related intervention programs.
- Central cancer registry data allows new etiologic, prevention, and control research in sub-populations of the state, such as racial and ethnic populations, or the medically underserved.
- Cancer registry data allows for studies of the efficacy of treatment, such as patterns of care or quality of care.

Types of Central Cancer Registries

◆ Types of General CCRs

● Regional

- Meet local needs
- Assess local risks
- Development of strategies for local prevention and early detection programs
- Direct allocation of local funds

Metropolitan Detroit Cancer Surveillance System



Greater Bay Area Cancer Registry



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- Regional central cancer registries collect data on patients within a defined geographic area, usually one or more counties within a state. These central cancer registries were sometimes established to meet the needs of the region prior to state-wide reporting. Now they continue to meet the needs of their region, and report their cases to the statewide central cancer registry.
- Two examples of regional central cancer registries are the Metropolitan Detroit Cancer Surveillance System (MDCSS) and the Greater Bay Area Cancer Registry (GBACR).
- MDCSS collects cancer data for all residents of a three-county area with a diverse population and urban, industrial environment. It was initiated in 1969, and became part of the National Cancer Institute's (NCI) Surveillance Epidemiology and End Results (SEER) Program in 1973. When the state-wide Michigan Cancer Surveillance Program (MCSP) was established in 1985, the MDCSS started reporting their data to MCSP while continuing to report to NCI-SEER.
- The Greater Bay Area Cancer Registry has a high proportion of Asian residents. The GBACR began in 1969 when the NCI selected five counties to participate in its Third National Cancer Survey, and it became a part of the SEER Program in 1973. The San Francisco Bay Area Registry was initially operated by the California Department of Health Services, and in 1982 moved to the Northern California Cancer Center. It wasn't until 1987 that cancer reporting became mandatory throughout the state of California.
- Data from these regional central cancer registries are used by local physicians and hospitals for long-range planning, evaluation of treatment, or evaluation of equipment needs. Local service agencies, professionals, and members of the general public use information on patterns of cancer in the reporting area for educational and program planning purposes. These databases are also used for research purposes. The data is used to describe subgroups of the reporting area population relating to cancer incidence, survival, stage of diagnosis, and treatment patterns. Registry data may also provide a catalyst for launching more extensive studies, which attempt to determine local environmental, socioeconomic, dietary, and occupational exposures that may have an impact on cancer patterns, as well as assessing the impact of screening, early detection and treatment on the length and quality of patient survival.

Types of Central Cancer Registries

◆ Types of General CCRs (continued)

● Statewide population-based

- Established for specific reason
- Established in conjunction with funding opportunities
 - NCI's SEER Program
 - CDC's NPCR
- Share common activities
- Reporting legislatively mandated
- Goal: complete reporting



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- Most state-wide central cancer registries were established for a specific reason, such as concern about the cancer burden in a specific sub-population, or suspected cancer clusters. As with the regional central cancer registries, some state-wide central cancer registries were established or enhanced with funding from NCI's SEER Program or the Centers for Disease Control and Prevention's (CDC's) National Program of Cancer Registries (NPCR).
- Reporting to the state central cancer registry is mandated by legislation in all states.
- A state-based central cancer registry collects, manages, and analyzes data about cancer cases on all the residents within that state. Collecting data on mortality is the responsibility of the state's vital statistics office, but the data is used by the central cancer registry to evaluate cancer mortality.
- One of the main goals of the central cancer registry is complete reporting. This is accomplished by requiring reporting from all medical facilities, including hospitals with and without a facility-based cancer registry, physicians' offices, therapeutic radiation facilities, freestanding surgical centers, or pathology laboratories. A state central cancer registry also matches its database to the state's death certificates to identify persons that have cancer listed as a cause of death but who have not been previously reported to the registry. Patients who have been diagnosed and/or treated for cancer in other states are also reported.
- State central cancer registries in different states frequently share the common activities of monitoring cancer trends over time: determining cancer patterns in various populations; guiding planning, and evaluation of cancer control programs, such as determining whether prevention, screening, and treatment efforts are effective; helping set priorities for allocating health resources; advancing clinical, epidemiologic, and health services research; and providing information for a national database of cancer incidence.

Types of Central Cancer Registries

◆ Types of General Registries (continued)

- Commission on Cancer's National Cancer Data Base (NCDB)
 - Not population-based
 - Voluntary participation by facilities
 - Collects data on all types of cancer
 - Uses nationally standardized data item and coding definitions
 - Data uses
 - Exploring trends in cancer care
 - Creating regional and state benchmarks
 - Serving as the basis for quality improvement

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The **National Cancer Data Base (NCDB)** is another type of general central cancer registry. It is not population-based, and participation in it is voluntary. It is a nationwide oncology outcomes database comprised of data submitted from more than 1,400 Commission on Cancer (CoC)-approved cancer programs in the United States and Puerto Rico. Some 75% to 80% of all newly diagnosed cases of cancer in the United States are captured at the institutional level and reported to the NCDB. Started in 1989, NCDB now contains approximately 20 million records from hospital cancer registries. Data on all types of cancer are tracked and analyzed using nationally standardized data item and coding definitions.

The data from NCDB are used to explore trends in cancer care, to create benchmarks for participating hospitals, and to serve as the basis for quality improvement. Participation by CoC-approved cancer programs in these studies is mandated by the CoC Cancer Program Standards. Thus, the NCDB collects the traditional data set and both one-time and ad hoc data sets. Data collected include patient characteristics (but not personal identifiers), tumor staging and histology characteristics, type of first course treatment administered, disease recurrence, and survival information.

Types of Central Cancer Registries

◆ Types of General CCRs (continued)

● National—United States

- SEER
 - Covers 26% of U.S. population
 - Active follow-up required
- NPCR
 - 96% of U.S. population
 - Active follow-up not required
- Four states receive funding from both SEER and NPCR



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In the United States there are two national population-based central cancer registries, the SEER Program and the NPCR.

- Established by The National Cancer Act of 1971, the SEER Program began collecting data on cancer cases in 1973 in five states and the two metropolitan areas. Over the next 30 years, the SEER program expanded, adding other specific populations of interest, such as Hispanics, American Indians, Alaska Natives, and Hawaiian/Pacific Islanders. SEER currently collects and publishes cancer incidence and survival data from population-based cancer registries covering approximately 26% of the US population. The SEER Program includes stage of cancer at the time of diagnosis and patient survival (follow-up) data.
- Recognizing the need for more complete local, state, and national cancer incidence data, the Cancer Registries Amendment Act, enacted by Congress in 1992, authorized CDC to administer the NPCR. NPCR provided planning grants to states without central cancer registries and grants to enhance existing state population-based central cancer registries. Before NPCR was established, 10 states had no CCR, and most states with central cancer registries lacked the resources and legislative support they needed to gather complete data. Today, NPCR supports central cancer registries in 45 states, the District of Columbia, Puerto Rico, and U.S. Pacific Island Jurisdictions. These data represent 96% of the U.S. population. NPCR does not require active follow-up.
- Compilation of central cancer registry data at a national level makes possible additional etiologic, prevention, and control research related to less common cancers such as brain tumors and childhood cancers whose numbers might be too small on a regional or even state-wide basis to be representative.

Types of Central Cancer Registries

◆ Types of General CCRs (continued)

● National—Other countries

- Finnish Cancer Registry
- National Cancer Registry of Ireland
- Cancer Registry of Slovenia
- Japan – 9 prefecture central registries
- China – more than 12 population-based registries
- Central and South American national registries
 - Columbia, Costa Rica, Cuba, Ecuador, Guatemala, Panama, Paraguay, Uruguay, Venezuela



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Many other countries around the world also have national central cancer registries. The ninth volume of the International Agency for Research on Cancer's *Cancer in Five Continents* for the period 1998–2002 was released in November 2007, and includes comprehensive data on cancer incidence from 300 regional or national populations worldwide.

- The **Finnish Cancer Registry** is a central registry that has maintained a nation wide database on all cancer cases in Finland since 1953. It is an internationally active institute for statistical and epidemiological research and includes a Mass Screening Registry as one of its departments.
- The **National Cancer Registry of Ireland** (Eire) was established in 1991 as a county-wide population-based registry. Since 1994, it has been collecting comprehensive cancer information for the whole population of the Republic of Ireland.
- The **Cancer Registry of Slovenia** was founded in 1950. Located at the Institute of Oncology in Ljubljana, it is involved in all aspects of cancer epidemiology. In addition to the central cancer registry of Slovenia, the Institute provides the services for the hospital-based cancer registry of the Institute of Oncology, Epidemiology Unit for epidemiologic studies and the newly established Cancer Screening Registry, a unit that is in charge of coordinating the nationally organized cervical cancer screening program.
- **Japan** does not have a national program of cancer registries, but estimates national statistics based on data from ten prefectures with central cancer registries.
- **China** has more than a dozen population-based central cancer registries in its provinces and major cities.
- Many of the countries in Central and South America have national population-based registries. Other countries in this area have hospital-based registries in the major cancer treatment facilities in the country.

Types of Central Cancer Registries

◆ Types of General CCRs (continued)

● International

➤ International Association of Cancer Registries

- Fosters exchange of information between CCRs internationally
- Improves data quality and comparability
- Publishes *Cancer Incidence in Five Continents*

➤ Middle East Cancer Consortium (MECC): Cancer Registry Project

- Partners: NCI, Cyprus, Egypt, Israel, Jordan, the Palestinian Authority, and Turkey
- Objective: Reduce incidence and impact of cancer in the Middle East through collaborative research

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- The **International Association of Cancer Registries (IACR)**, founded in 1966, is a non-governmental organization and has been in official relations with the World Health Organization since January 1979. IACR is a professional society dedicated to fostering the aims and activities of cancer registries worldwide. IACR was established primarily for population-based registries that collect information on the occurrence and outcome of cancer in defined population groups, usually the inhabitants of a city, region, or country. IACR was created to foster the exchange of information between cancer registries internationally, improving data quality and comparability between registries. To encourage comparisons between different registries, countries, and over time, the IACR has developed registry practices and standard definitions for collecting, coding, and presenting data. IACR also publishes *Cancer Incidence in Five Continents*, a series of monographs published every five years, which has become the reference source of data on the international incidence of cancer.
- Established in 1996, the **Middle East Cancer Consortium (MECC)** is a unique partnership between the United States and the Ministries of Health of Cyprus, Egypt, Israel, Jordan, the Palestinian Authority, and Turkey. The objective of the MECC is to reduce the incidence and impact of cancer in the Middle East through the solicitation and support of collaborative research. One of MECC's major activities has been the Cancer Registry Project (CRP). The CRP aims to support population-based cancer registries within MECC members and develop linkages among them. In 2006, *Cancer Incidence in Four Member Countries (Cyprus, Egypt, Israel and Jordan) of the Middle East Cancer Consortium (MECC) Compared with U.S. SEER* was released. The monograph compiles information on cancer incidence between 1996 and 2001, drawn from the cancer registries in four MECC member countries.

Types of Central Cancer Registries

◆ Specialty CCRs

● Goals

- Data collection
- Educational opportunities
- Patient support
- Advocacy

● Structure

- Data collection methods may be different
- Data content may be different
- Standard cancer data coding may not be used

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Specialty central cancer registries are established to collect and maintain data either on a particular type of cancer or within a particular population. There are different types of specialty registries and their goals are usually specific to the type of cancer they support. In addition to data collection, these central cancer registries often provide education to participants, family members, and health care providers and support for those who may be living with cancer.

A specialty central cancer registry is often structured differently from a general registry. The data can be very focused, may not be collected from hospitals or other facilities, and may not use standardized data items and data definitions because they are independent of the cancer surveillance system in the area they cover.

Types of Central Cancer Registries

◆ Types of Specialty CCRs

● Disease Registries

- Central Brain Tumor Registry of the United States
- Familial Cancer Registries
 - Gilda Radner Familial Ovarian Cancer Registry
 - National Familial Lung Cancer Registry
 - Familial Pancreatic Cancer Registry
- Inflammatory Breast Cancer Registries

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First, we will discuss the central cancer registries for specific cancers.

- The **Central Brain Tumor Registry of the United States (CBTRUS)** was established in 1992 as a not-for-profit corporation to provide a resource for descriptive statistical data on all primary brain tumors irrespective of behavior. Data on cancers diagnosed prior to 2004 were compiled voluntarily from selected state central cancer registries. Data on cases from 2004 forward will be obtained from the NPCR.
- Familial central cancer registries often provide educational opportunities for those who want to learn more about a particular type of cancer, and support for those who may be living with it.
- One example is the **Gilda Radner Familial Ovarian Cancer Registry**, which collects cancer information from those families with two or more relatives having ovarian cancer.
- Another familial CCR is the **National Familial Lung Cancer Registry**, whose goals are to further the understanding of the causes of lung cancer beyond smoking, and to serve as an educational resource for persons at risk for lung cancer.
- The **Familial Pancreatic Cancer Registry** studies genetic factors that increase the risk for pancreatic cancer. This central cancer registry provides education to participants, family members, and health care providers.
- There are two **Inflammatory Breast Cancer Registries (IBCR)**, one associated with the George Washington University Medical Center and the other associated with the Tufts/New England Medical Center. Participation involves patients filling out forms regarding their medical history. Patients are offered the choice to give access to their stored diagnostic biopsies. IBCR is building a 'bank' of IBC tumors so that researchers can determine differences when IBC is compared to other types of breast cancer.

Types of Central Cancer Registries

◆ Types of Specialty Registries (continued)

● Special populations

➤ Military

- Veterans Administration Central Cancer Registry
- Department of Defense (ACTUR)

➤ American Indian/Alaska Native/Aboriginal Registries

- Inuit Cancer Registry
- Cherokee Nation Cancer Registry

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As mentioned, some central cancer registries focus on special populations of cancer patients. Examples include military central cancer registries, and American Indian/Alaska Native central cancer registries. Two examples of military central cancer registries are the Veterans Administration (VA) Central Cancer Registry, and the Department of Defense's (DoD) Automated Central Tumor Registry (ACTUR).

- There are approximately 140 VA medical centers diagnosing and/or treating patients with cancer. The **VA** central cancer registry, at VA Headquarters in Washington, DC, was implemented under the *National Cancer Directive*, and aggregates the data collected by the medical centers' cancer registries. VA system-wide data collection and reporting started in 1995.
- **ACTUR**, established in 1986, was developed to facilitate inter-hospital usage by military beneficiaries, to promote the cost savings associated with a single inter-hospital system, and to provide the ability to produce automated reports and studies on a Department of Defense-wide basis. Originally developed as a multi-hospital data collection system only, a central cancer registry function has been established at the Armed Forces Institute of Pathology, and data from the year 1998 to the present are currently being edited and consolidated. Through implementation of this central cancer registry function, it is hoped that quality research data will be available for tracking and analyzing DoD total force and beneficiary cancer incidence trends.

Two examples of American Indian/Alaska Native central cancer registries are the Inuit Cancer Registry and the Cherokee Nation Cancer Registry.

- **Cherokee Nation Cancer Registry.** The availability of limited, yet good quality data on cancer incidence, treatment, and survival trends for American Indians is a problem in Oklahoma where it is estimated that there is significant under-reporting of cancer mortality in this population. In partnership with the Cherokee Nation of Oklahoma, the NCI has funded a pilot cancer registry with the goal of building a central cancer registry that will be able to meet SEER standards in case finding, patient follow-up, data processing, data reporting, and quality assurance. The target population includes all American Indians residing in the Cherokee Nation's 14-county tribal jurisdictional service area who are eligible for health care through tribal or Indian Health Service facilities.
- The **Inuit Cancer Registry** was established in response to concerns about reported increases in the number of cancer cases among Inuit and other aboriginal peoples in the Canadian north. There were questions about the accuracy of the existing reports since there were no systematic and long term records documenting cancer in this population and no verifiable way of knowing if the concerns were founded.

Types of Central Cancer Registries

◆ Types of Specialty Registries (continued)

● Special populations

➤ Pediatric

- Cancer Registry at Children's Hospital of Los Angeles
- Childhood Cancer Registry for Belarus
- United Kingdom's National Childhood Tumor Registry

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Another special central cancer registry focuses on cancer in children. Pediatric central cancer registries exist in the US and in many other countries. In the United States, many pediatric cancer registries are associated with children's hospitals, but in other countries they may be nationally-based.

- The **Cancer Registry at Children's Hospital of Los Angeles (CHLA)** was established in 1968, and is the largest pediatric cancer registry in California, reporting approximately 275 cases annually. There are nearly 4,200 patients in CHLA Cancer Registry's active database representing patients diagnosed after 1/1/85, with an additional 2,500 historical cases diagnosed between 1968 and 1984. Patients are followed annually throughout their lives.
- The computer-based **Childhood Cancer Registry for Belarus (CCRB)** was established in 1996, and is located at the University Children's Medical Center, Minsk, Belarus. A summary of all pediatric cancers diagnosed from 1978 to 1994 has been compiled from state-maintained records. Seventy percent of the radioactive fallout from the 1986 Chernobyl Power Plant explosion fell on Belarus. A recent report from this central cancer registry is the first comprehensive analysis of childhood cancer from the contaminated regions. The CCRB has confirmed an increase in thyroid cancer in Belarus and has identified a possible increase in childhood brain tumors, which will need further study before any conclusions can be reached. The Registry also tracks the severity of disease and survival after diagnosis, so the behavior of childhood cancer in Belarus can be studied. Tracking cases and their response to treatment will be used for additional research and assist in directing aid to the areas where it is most needed.
- The Childhood Cancer Research Group (CCRG), based in the University of Oxford, maintains the **United Kingdom's National Childhood Tumor Registry (NRCT)**, a population-based central cancer registry of malignancies and benign brain tumors diagnosed in children less than 15 years of age who live in England, Wales or Scotland at the time of diagnosis. The principal tasks of the NRCT are to use their data to fulfill the basic public health functions of a central cancer registry through description and analyses of trends and distributions of cancer incidence, mortality and survival; to distribute NRCT data to potential users who make legitimate requests; and to undertake a variety of more complex national and international research studies. Many of these studies are undertaken collaboratively with others outside the CCRG, and include the descriptive, analytical and genetic epidemiology of childhood cancer; studies of medical care and outcomes in those in whom it is diagnosed; and the preventive/policy measures by which childhood cancer occurrence might be reduced.

Role of Statewide CCRs in the U.S.

- ◆ **Monitor cancer trends over time**
- ◆ **Determine cancer patterns within populations**
- ◆ **Guide planning and evaluation of cancer control programs**
- ◆ **Help set priorities for allocating health resources**
- ◆ **Advance clinical, epidemiologic, and health services research**
- ◆ **Provide information for a national database of cancer incidence**

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Now we will change our focus to a detailed look at U.S. statewide central cancer registries and how their data are used. To do this, we need to first understand what these central cancer registries are designed to do.

This slide lists some common state-wide central cancer registry activities. We can see that all of them involve the use of the data that is routinely collected.

Statewide CCRs Use of Data

◆ Data use categories

- Comprehensive cancer control
- Detailed incidence/mortality statistics
- Health event investigation(s)
- Needs assessment/program planning
- Program evaluation
- Epidemiologic studies

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Uses of central cancer registry data can be categorized into several types of activities. The categories listed on this slide are those identified by the 2007 NPCR Standards. We will discuss examples of each.

Central Cancer Registry Use of Data

◆ Comprehensive cancer control

● Planning and implementation

- For conducting needs and capacity assessments
- To promote evidenced-based decision making
- Help focus cancer prevention and control efforts
- Serve as a baseline for evaluating progress in cancer plan implementation

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The first category of data use is for comprehensive cancer control. Planning and implementation for comprehensive cancer control efforts benefit from the cancer data that are collected and analyzed in central cancer registries. The data can be presented to individuals conducting needs- and capacity-assessments to promote evidenced-based decision making on a local level. These data can help focus cancer prevention and control efforts. The data can also serve as a baseline for evaluating progress in cancer plan implementation. All state central cancer registries have the data elements essential for this application.

Central Cancer Registry Use of Data

◆ Comprehensive cancer control (continued)

- Example 1: New Jersey Comprehensive Cancer Control Plan
 - Used New Jersey State Cancer Registry data
 - Developed historical baselines
 - Provide recommendations for cancer control and prevention initiatives

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The first example of this type of central cancer registry data use is from New Jersey. The New Jersey Comprehensive Cancer Control Plan (NJCCCP) used data from the **New Jersey State Cancer Registry** (NJSCR) to develop historical baselines and provide recommendations for cancer control and prevention initiatives.

In 2003, state-funded county evaluators were hired to develop a needs and capacity assessment in each of New Jersey's 21 counties. NJSCR data for 1996–2000 were used to generate rates and counts for each county, and for the cancers addressed in the NJCCCP. Data were provided in sufficient detail and in formats that were easy to understand for county evaluators of differing backgrounds. Data were presented by race/ethnicity, gender, stage of disease, and age, to enable county evaluators to pinpoint local cancer problems among specific populations. The data were incorporated into county capacity and needs assessments and have been integral to setting local cancer control priorities. The data were used to determine the best allocation of resources for targeting cancer prevention and control, which would have the most impact on a county's cancer burden.

In addition, the data helped local experts prioritize different initiatives, such as smoking cessation programs versus increasing cancer screening programs, in various communities. For example, one county noted that its cancer incidence rates for all cancer sites combined were slightly lower than the overall state rate, yet were higher than the national rates. On closer study, the county also noted that rates for cancers of the breast and lung were both higher than the state and national rates. This finding indicated that trends for these cancers should be monitored to help inform the New Jersey Cancer Coalition.

Central Cancer Registry Use of Data

◆ Comprehensive cancer control (continued)

- Example 2: Minnesota Cancer Surveillance System
 - Showed a persistent excess of mesothelioma in northeastern Minnesota
 - Resulted in legislative funding to look for cases of other occupation-related disease
- Example 3: New York State Cancer Registry
 - Demonstrated distribution of cancer risk factors
 - Developed targeted statewide public education programs

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Another example of central cancer registry data use for comprehensive cancer control is from Minnesota. Data from the **Minnesota Cancer Surveillance System** showed a persistent excess of mesothelioma in northeastern Minnesota. This rare type of cancer has only one known cause: asbestos exposure. This observation resulted in legislative funding to look for cases of other occupation-related disease.

Another example comes from New York. Cancer incidence data collected by the **New York State Cancer Registry** was sorted by zip code. Using this data and state-of-the-art mapping techniques, the distribution of cancer risk factors were shown and targeted statewide public education programs were developed.

Central Cancer Registry Use of Data

◆ Detailed incidence/mortality statistics

● Annual Reports

- NPCR 2007 standards
 - Within 12 months of the end of the diagnosis year with data are 90% complete
 - Within 24 months of the end of the diagnosis year with data are 95% complete
- Specific requirements for minimum contents for each report
 - 12 months
 - Preliminary monitor of the top cancer sites
 - Incidence rates, counts, or proportions
 - 24 months
 - Age-adjusted incidence and mortality rates

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The second category of central cancer registry data use is detailed incidence and mortality statistics, usually published in an annual report and posted to publicly available websites.

From its inception, the NPCR recognized the importance of reporting central cancer registry data. NPCR's 2007 standards have requirements for publication of both 12-month and 24-month data. These standards have two requirements:

- 1) Within 12 months of the end of the diagnosis year with data that are 90% complete, the central cancer registry produces preliminary pre-calculated data tables in an electronic data file or report of incidence rates, counts, or proportions for the diagnosis year by SEER site groups as a preliminary monitor of the top cancer sites within the state/territory.
- 2) Within 24 months of the end of the diagnosis year with data that are 95% complete, the central cancer registry produces pre-calculated data in tables in an electronic data file or report. The report includes, at a minimum, age-adjusted incidence rates and age-adjusted mortality rates for the diagnosis year by sex for SEER site groups, and, where applicable, by sex, race, and ethnicity.

In addition to data on incidence and mortality, annual central cancer registry reports may contain information on cancer risk factors, stage of disease, screening, and prevention and treatment.

To be of value, data must be used. Publication of detailed state-specific cancer statistics for racial and ethnic populations can be used to inform and direct public health efforts toward eliminating race- and ethnicity-based disparities in cancer risk factors, screening behaviors, and other cancer-related problems as well as aid comprehensive cancer control efforts.

Next we will look at some examples of how central cancer registries have used this data.

Central Cancer Registry Use of Data

◆ Detailed incidence/mortality statistics

(continued)

- Example: Cancer Data Registry of Idaho (CDRI)
 - *Cancer in Idaho by Race and Ethnicity*
 - Demonstrated that cancer cases are unevenly distributed by variables such as income, geography, and race/ethnicity

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An example of one of these reports comes from Idaho. Using updated race and ethnicity information, the **Cancer Data Registry of Idaho** (CDRI) published *Cancer in Idaho by Race and Ethnicity* for 1990 through 2001. This was the first Idaho-specific publication to include detailed cancer statistics, including rates, for minority populations. Both CDRI and the Idaho Division of Health staff have conducted presentations about the report. They have demonstrated that cases of cancer are unevenly distributed by variables such as income, geography, race, and ethnicity.

Central Cancer Registry Use of Data

◆ Detailed incidence/mortality statistics

(continued)

● Other special reports

- Geographic reports
- Cancer disparities
- Reports by race and ethnicity
- Site-specific cancer reports
- Pediatric cancer reports

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In addition to data on incidence and mortality in annual reports, central cancer registries may publish other specialty reports. These reports may be on specific geographic areas, on cancer disparities, or on specific race or ethnic groups, site-specific reports, or other specific populations such as pediatric cancer.

Central Cancer Registry Use of Data

◆ Detailed incidence/mortality statistics

(continued)

● Examples of special reports

- South Carolina Central Cancer Registry's *Legislative District Cancer Profiles*
- Kentucky Cancer Registry data by county
- *Cancer Disparities in Idaho*
- California Cancer Registry: Race/ethnicity and socioeconomic status in risk of developing breast cancer
- *Cervical Cancer Control in Minnesota*
- *Georgia Childhood Cancer Report*

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Here are some examples of how the central cancer registry data has been used in special reports.

- The **South Carolina Central Cancer Registry** publishes *Legislative District Cancer Profiles*, which are two-page summaries containing general and specific cancer incidence and mortality information for each of their Senate and House Districts.
- The **Kentucky Cancer Registry** publishes central cancer registry data by county.
- The **Idaho Cancer Registry** published *Cancer Disparities in Idaho Phase I – Incidence: Understanding Disparities in Cancer Incidence Using Individual and Area-Based Measures* to describe and understand disparities in cancer incidence patterns by race and ethnicity, census tract-level poverty, urban-rural gradient, and geographic area. This information will be used to develop appropriate prevention and screening strategies.
- The **California Cancer Registry** and California Women's Health Survey data were used to investigate questions about the relationship between race, ethnicity, and socioeconomic status in the risk of developing breast cancer. They also investigated how these variables are related to the stage of breast cancer at diagnosis.
- The **Minnesota Cancer Surveillance System** published *Cervical Cancer Control in Minnesota: Assessing its Effectiveness with Data from the Minnesota Cancer Surveillance System* to assess the cervical cancer control efforts within the state.
- The *Georgia Childhood Cancer Report* prepared by the **Georgia Comprehensive Cancer Registry** includes both childhood cancer incidence and mortality. The data in this report will be used to guide statewide and local cancer control efforts to assure that every child with cancer in Georgia has access to the best treatment, to improve the quality of information about childhood cancer and to search for causes so that childhood cancer can be prevented.

Central Cancer Registry Use of Data

◆ Health event investigations

- Most challenging activities faced by central cancer registries
- Frequently no excess in cancer cases is found
- Opportunities
 - Provide cancer control and other health-related information
 - Build community relationships
 - Implement public health interventions

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The next category of CCR data use is health event investigations, also known as cancer cluster investigations. Responding to cancer concerns is among the most challenging activities faced by central cancer registries. In most circumstances, no excess in cancer cases is found or, if an excess is found, the excess can be more readily attributed to behavioral risk factors such as tobacco use than to environmental contamination. Even though community reactions to such findings are often less than positive, these situations present invaluable opportunities to provide cancer control and other health-related information, and to build relationships among community groups, local/county/state public health, local health care providers, and other people that are essential to improving public health.

Community-raised cancer concerns provide a unique opportunity to implement public health interventions aimed at larger cancer control and other health-related issues. Responses to community cancer concerns should include general information on cancer and cancer risk factors and, to the extent possible, information on the community's levels of cancer risk factors, such as tobacco use and obesity, as well as other community health indicators. By using the relatively informal public availability session approach, in which a variety of public health and environmental programs set up informational displays and interact individually with community members, public health partners address the concern together. Furthermore, the community gains "added value" by receiving information about other health issues and referrals to public health personnel who can help them address these issues. Thus, what could be perceived as a negative interaction can become an opportunity to inform, build relationships, and improve public health.

Central Cancer Registry Use of Data

◆ Health event investigations (continued)

- What is a cancer cluster?
 - Greater than expected number of cancer cases
 - Within a group of people
 - In a geographic area
 - Over a period of time
- Need to understand key facts about cancer cluster
- Need internal management system

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What is a cancer cluster? CDC defines a cancer cluster as a greater than expected number of cancer cases that occurs within a group of people, in a geographic area, or over a period of time. A person might suspect that a cancer cluster exists when several loved ones, neighbors, or coworkers are diagnosed with cancer. However, what appears to be a cluster may actually reflect the expected number of cancer cases within the group or area.

When the possible existence of a cancer cluster is considered in an area, it is important to remember a few key facts:

- 1) cancer is a common disease, affecting about one in three people in their lifetime;
- 2) the term cancer refers not to a single disease, but instead to a group of related yet different diseases;
- 3) a cancer cluster may be due to chance alone, like the clustering of balls on a pool table;
- 4) an apparent cancer cluster is more likely to be genuine if the cases consist of one type of cancer, a rare type of cancer, or a type of cancer that is not usually found in an age group.

When a cancer cluster suspicion is reported to a state health agency, in many instances they will not be able to demonstrate an excess of the condition in question or establish an etiologic linkage to an exposure. Nevertheless, a systematic, integrated approach is needed for responding to reports of clusters.

Health agencies need to understand the potential legal ramifications of reported clusters, how risks are perceived by the community, and the influence of the media on that perception. Organizationally, each agency should have an internal management system to assure prompt attention to reports of clusters. Such a system requires the establishment of a locus of responsibility and control within the agency and of a process for involving concerned groups and citizens, such as an officially constituted advisory committee. Written operating procedures and dedicated resources may be of particular value.

A CDC survey revealed that most state health departments' strategies for cluster response are based on CDC's "Guidelines for Investigating Clusters of Health Events" with some modifications. These guidelines focus on noninfectious health events such as chronic diseases, injuries, and birth defects. Numerous related issues, such as the epidemiologic workup of infectious disease outbreaks, the assessment of the health effects of environmental exposures, the prospective detection of clusters, and the investigation of interpersonal networks are not addressed by these guidelines.

Central Cancer Registry Use of Data

◆ Health event investigations (continued)

- CDC Guidelines for Investigating Clusters of Health Events
 - <http://www.cdc.gov/mmwr/preview/mmwrhtml/00001797.htm>
- Recommendations
 - Gather information
 - Discuss initial impressions
 - Provide a written response
 - Maintain log of initial contacts
 - Notify health agency's public affairs office

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These are the procedures that CDC recommends.

- Gather identifying information on the caller, unless anonymity is requested. Include name, address, telephone number, and organization affiliation, if any. If anonymity is requested, advise the caller that the inability to follow up may hinder further investigation.
- Gather initial data on the potential cluster or suspected health event, suspected exposure, number of cases, geographic area of concern, time period of concern, and how the caller learned about the cluster.
- Obtain identifying information on persons affected such as their name, sex, age or birthdate, age at diagnosis, age at death, occupation, race, diagnosis, date of diagnosis, date of death, address (or approximate geographic location), telephone number, length of time in residence at site of interest, contact person such as a family member or a friend, the method for contact, and a physician contact. In some instances, the health official may choose not to collect identifying information during the first contact but instead to gather it during several contacts.
 - Discuss initial impressions with the caller. Several concerns frequently arise:
 - 1) A variety of diagnoses speaks against a common origin.
 - 2) Cancer is a common illness (with a one in three lifetime probability). The risk increases with age, and cases among older persons are less likely to be true clusters.
 - 3) Major birth defects are less common than cancer but still occur in 1%–2% of live births.
 - 4) Length of time in residence must be substantial to implicate a plausible environmental carcinogen because of the long period of latency required for most known carcinogens.
 - 5) Cases that occurred among persons now deceased may not be helpful in linking exposure to disease because of the lack of information on exposure and because of possible confounding factors.
 - 6) Rare diseases may occasionally "cluster" in a way that is statistically significant, but such an occurrence may be a statistical phenomenon not related to exposure.
- Request further information on cases, obtain more complete enumeration, and plan a follow-up telephone contact, as needed.
- Assure the caller that he or she will receive a written response. Often, the written response simply confirms what has already been communicated by telephone.
- Maintain a log of initial contacts, whether they are made in writing, by telephone, or in person. The log should include the date, time, caller identification, health event, exposure, and geographic area. Follow-up contacts should be logged in as well, with a brief note as to purpose and result. If possible, the log should be cross referenced and computerized so that all personnel concerned will have the same information.
- Notify the health agency's public affairs office or its equivalent about the contact. In many agencies, this action is analogous to notifying the commissioner's office of a press contact.

Central Cancer Registry Use of Data

◆ Health event investigations (continued)

➤ Example 1: West Virginia Cancer Registry

- Environmental testing did not produce acceptable answers
- Detailed investigations showed evidence of elevated rates of pancreatic, lung, and other tobacco-associated cancers
- Public availability session held to address the community's concerns
- Community started to address the identified cancer-causing agents and began working together to prevent cancer and other health problems.

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Our first example of a public health investigation comes from West Virginia. The **West Virginia Cancer Registry** received an inquiry about a possible cancer cluster in a small coal mining town in a rural county. Community members had already collected the names of many people who were reported to have had cancer and had also collected unverified reports of alleged dumping of unknown substances during the 1980s. Unlike many other cluster reports, which tend to focus on a single type of cancer, these community members reported concern about many types of cancer.

Environmental testing had not produced the types of answers some members of the community believed it would, and press coverage was becoming increasingly strident. Detailed investigations of all cancers in the county and in the target area showed elevated rates of pancreatic, lung, and other tobacco-associated cancers. Further investigation by medical record review of the cases of pancreatic cancers found strong associations with diabetes and tobacco use, as shown in other epidemiologic studies.

Through collaborative efforts of West Virginia's Comprehensive Cancer Control Program, the Tobacco Control Program, the Office of Environmental Health Services, the local health department, other health promotion programs, and state and federal environmental protection programs, a public availability session was held to address many of the community's concerns. Although some community members remained convinced that chemical dumping was the cause of cancer in their community, other interested parties started to address cessation from tobacco use and factors associated with diabetes.

Central Cancer Registry Use of Data

◆ Health event investigations (continued)

➤ Example 2: Pennsylvania Cancer Registry

- Increased incidence of polycythemia vera
- Involved Agency for Toxic Substances and Disease Registry (ATSDR)
- No commonalities were found among the cases

● Example 3: South Carolina Central Cancer Registry

- Conduct 30–40 community cancer assessments each year
- One true cancer cluster has been identified

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Another example of a health event investigation comes from Pennsylvania. The U.S. Agency for Toxic Substances and Disease Registry (ATSDR) became involved after residents expressed concern when 97 cases of polycythemia vera (PCV) in three counties were reported to the **Pennsylvania Cancer Registry** between 2001 and 2005. Based on its population, the region should have reported about 25 cases. ATSDR's task was to confirm the cases that appeared in the central cancer registry and to find cases the registry might have missed. Scientists also tried to find commonalities among PCV patients, including their proximity to toxic waste sites. However, no commonalities were found among the cases with respect to their water source, residential history, occupational history.

The **South Carolina Central Cancer Registry** (SCCCR) reports that they conduct approximately 30–40 community cancer assessments each year. Since the SCCCR began investigating community cancer inquiries, only one true cancer cluster has been identified in South Carolina.

Central Cancer Registry Use of Data

◆ Health event investigations (continued)

➤ Example 4: California Cancer Registry

- Excess of cancer cases in a graduating class
- Assessment by CCR suggested a significantly elevated number of cancer cases
- Confirmed an excess of cancer in a specific graduating class
- No other classes had an excess of cancer
- Cancer rates in other areas of the community were not elevated
- Other age groups did not have elevated cancer rates

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The next example comes from California. The California Department of Health Service's **California Cancer Registry (CCR)** which is part of the Cancer Surveillance Section (CSS), and the Environmental Health Investigations Branch (EHIB), along with the Contra Costa County Department of Health Services, investigated a reported excess of cancer cases in the 1985 graduating class of Monte Vista High School (MVHS) in Danville, CA. While organizing their 5-year reunion, members of the class of 1985 became alarmed about the number of cancer cases among their former classmates. The local newspaper was contacted, and interviews with some of the cases and other graduates were published in the spring of 1991. This caused considerable concern in the community and resulted in numerous calls to the county and state health departments.

An initial assessment by CCR suggested that the seven cases occurring in the 1985 graduating class were significantly more than the one case that would be expected for a class of approximately 350 students. An investigation was undertaken to further examine the observed excess. The objectives of the study were to determine if the cancer excess was confined to the class of 1985; if the cancer excess was a manifestation of a school cohort excess or a residential cohort excess; and if there was evidence of a cancer excess for the same age group in other parts of Danville and; if there was evidence of a cancer excess in other age groups in the same geographic area.

The conclusion of the study was that DHS confirmed an excess of cancer in young adults who attended Monte Vista High School and graduated in 1985. No other classes appeared to have an excess. Cancer rates in areas outside of the school attendance area were not elevated, and other Danville age groups did not have elevated cancer rates. Although it was difficult to completely reconstruct the school environment for the class of 1985, a school inspection in 1992 uncovered no carcinogenic exposures. A questionnaire demonstrated no exposures or personal attributes or behaviors that were shared by most of the cases in the class of 1985. Although the class of 1985 cases lived in the attendance area longer than the other cases, no residential risk factors for cancer were identified. Other age groups in the attendance area did not have elevated cancer rates. No exposures that would be selective for 15–24 year olds were identified through the questionnaire or other phases of the investigation.

The investigation did not uncover any unusual cancer-causing exposures shared by the group of young adults. Perhaps reassuring to other parents that there was no evidence that graduating classes other than 1985 have a cancer excess, and no environmental factors were identified in the Monte Vista School environment to set it apart from any other school in California. DHS has no other studies pending, and as a result of its investigation, does not recommend further study at this time.

Central Cancer Registry Use of Data

◆ Health event investigations (continued)

➤ Example 5: New Jersey State Cancer Registry (NJSCR)

- Elevation of childhood cancer in the Toms River area
- ATSDR evaluated possible risk factors
- Public Health Response Plan developed
- NJSCR expanded evaluation of childhood cancer statistics
- Dover Township and Toms River area only municipality with statistically significant elevation in overall childhood cancer rates
- Increased risk of leukemia in female children due to prenatal exposure to drinking water from a contaminated well field and contaminated air from a chemical manufacturing plant

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Our next example comes from New Jersey. The occurrence of childhood cancer had been a concern in the Dover Township/Toms River area of Ocean County for many years. In 1995, the New Jersey Department of Health and Senior Services (NJDHSS) released an analysis of childhood cancer using **New Jersey State Cancer Registry** data for the period 1979 through 1991. The finding of a statistically significant elevation in overall childhood cancer heightened community concerns about cancer in children, and its possible relationship to environmental pollution issues in and around the township.

The NJDHSS has worked closely with the ATSDR to evaluate possible risk factors (including environmental exposures), that might be related to the elevated incidence of childhood cancer in Dover Township. The NJDHSS and ATSDR, with community-based input from the Citizens Action Committee on Childhood Cancer Cluster (CACCCC) and the Ocean County Health Department, developed a Public Health Response Plan. The Plan included an update and re-evaluation of childhood cancer rates, public health evaluations of potential environmental exposures to hazardous chemicals in the environment, and public health education efforts. Public health activities were later expanded to include a case-control epidemiologic study.

The NJDHSS conducted an expanded evaluation of childhood cancer statistics for the period 1979 through 1995 for Ocean County and Dover Township. The report of this analysis was completed and released in December 1997. Dover Township was found to be the only municipality in Ocean County with a statistically significant elevation in overall childhood cancer rates. In the township as a whole, as well as in the Toms River section of the town, both leukemias and brain cancers were elevated, particularly among female children under age 5 years.

Based on findings from the Public Health Response Plan, an epidemiologic study was launched in 1998. The report of the epidemiologic study was released for public comment in December 2001, and the final version was released in January 2003. The study found that prenatal exposure to two environmental factors in the past were associated with increased risk of leukemia in female children. These exposures were access to drinking water from the Parkway well field after the time that the well field was most likely to be contaminated, and air pollutant emissions from the Ciba-Geigy chemical manufacturing plant. These exposures are no longer occurring because of closure of the Ciba-Geigy plant and remedial actions by state and federal environmental agencies.

Central Cancer Registry Use of Data

◆ Needs assessment/program planning

- Problem identification process
- What is and what should be
 - Example 1: Kentucky Cancer Registry
 - CCR data used to identify areas with high rates of late-stage and low rates of early-stage breast cancer
 - Expanded mammography outreach activities in identified communities
 - Percentage of KY women diagnosed with late-stage breast cancer declined from 35% to 30%

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The next category of cancer data use is needs assessment and program planning. Needs assessment is defined as a problem identification process that looks at the difference between "what is" and "what should be" for a particular situation.

The first example comes from Kentucky. In the early 1990s statewide **Kentucky Cancer Registry** data were used to identify areas of the state that had high rates of late-stage and low rates of early-stage breast cancer. As a result, Kentucky expanded mammography outreach activities in these communities. By 1996, the percentage of Kentucky women diagnosed with late-stage breast cancer had declined from 35% to 30%. By detecting these cancers early, thousands of lives were spared, and an estimated \$4.7 million in treatment expenditures was saved.

Central Cancer Registry Use of Data

◆ Needs assessment/program planning

(continued)

- Example 2: Arizona Cancer Registry
 - Area of state had high percentage of late stage breast cancer cases
 - Breast cancer screening planned for targeted areas
- Example 3: Kansas Cancer Registry
 - CCR data used to identify locations with limited access to radiation treatment centers and clinics

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Another example comes from the **Arizona Cancer Registry (ACR)**. Data on the stage of cancer at diagnosis were coded and analyzed by zip code, which showed that the northeastern part of the state had the highest percentage of breast cancer cases diagnosed at a late stage, 42% compared to the state average of 30%. By using data from the ACR to identify the areas with the highest levels of late-stage breast cancer, additional outreach efforts that encouraged breast cancer screening were planned.

By using statewide **Kansas Cancer Registry (KCR)** data to examine cancer care in various communities, hospital administrators and physicians concluded that people in certain geographic locations lacked access to radiation treatment centers and clinics. KCR data were able to pinpoint communities needing cancer care facilities. As a result, new facilities were opened.

Central Cancer Registry Use of Data

◆ Program evaluation

➤ Example 1: New Mexico Tumor Registry

- Purpose: determine if statewide breast and cervical cancer screening services influenced trends in disease incidence and stage
- Assessed: breast and cervical cancer incidence trends before and after the screening program
- Demonstrated: use of screening program
 - improved detection of breast and cervical cancer
 - helped reduce incidence of advanced stages

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Central cancer registry data can also be used for any statewide program evaluation.

The first example comes from New Mexico. The **New Mexico Tumor Registry** (NMTR) sought to determine whether the breast and cervical cancer screening program influenced trends in disease incidence and stage. Trend data for breast and cervical cancer incidence and stage before and during implementation of the New Mexico Breast and Cervical Cancer Screening Program were assessed. Results showed that the incidence of cervical carcinoma *in situ* increased rapidly in 1991 when the screening program was implemented. The incidence for *in situ* breast cancer and local breast cancer also increased during the program implementation. Notably, a significant increase in incidence for regional and distant breast cancer from years prior to implementation declined during the period of program operation. Their conclusions were that the statewide screening program improved detection of breast and cervical cancer and helped reduce the incidence of advanced stages of breast cancer in a relatively short time period.

Central Cancer Registry Use of Data

◆ Program evaluation (continued)

- Example 2: Florida Cancer Data System
 - Assess effect of participation in Early Detection Program (EDP) on
 - stage at diagnosis
 - hazard of death
 - Florida Cancer Data System linked with EDP
 - Result: participation in EDP increased likelihood of breast cancer early detection and reduced hazard of death

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Another example comes from Florida. Previous studies by a research team had found that medically underserved minority women in the Miami-Dade County area of Florida were in need of breast cancer screening, and that there were problems with availability, accessibility, and acceptability of services. In response, a community-based comprehensive breast cancer screening program called the Early Detection Program (EDP) was established for medically underserved patients, in other words, those who lived in lower socioeconomic areas or who had limited or no health insurance to cover medical costs. Subsequently, another study was designed to assess the effect that EDP participation had on stage at diagnosis and on the hazard of death. To do this, existing data from the **Florida Cancer Data System** (FCDS) were linked with data from the EDP. Subjects identified as EDP participants were compared to non-participants with respect to disease stage at diagnosis and hazard of death. The results showed that EDP participants were 2.4 times as likely to present with a diagnosis of localized cancer as were non-participants, even after controlling for race and age at diagnosis. The conclusions from this study were that participation in the EDP increased the likelihood of early detection of breast cancer and reduced the risk of cancer-related death for medically underserved women in the Miami-Dade County area of Florida. Interestingly, white Hispanics showed a better survival rate than did both African-Americans and white non-Hispanics. Research also demonstrated the value of using existing central cancer registry data to evaluate a community-based program such as the EDP.

Central Cancer Registry Use of Data

◆ Epidemiologic studies

- Study of factors affecting the health and illness of populations
- Foundation and logic of interventions
- Many types of epidemiologic studies associated with central cancer registries
 - Example 1: New York State Cancer Registry
 - Researchers identify cancer patients to be interviewed about possible exposures
 - Identified possible association between alcohol intake and breast cancer

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This central cancer registry data usage category is for epidemiologic studies. Epidemiology is the study of factors affecting the health and illness of populations. It serves as the foundation and logic of interventions made in the interest of public health and preventive medicine. It is considered a cornerstone methodology of public health research, and is highly regarded in evidence-based medicine for identifying risk factors for disease and determining optimal treatment approaches to clinical practice.

Central cancer registries participate in epidemiologic studies in a variety of ways. Some central cancer registries actively participate in these studies and others have a more passive participation by providing the data that other investigators use as the basis for their research. Participation by central cancer registries in epidemiologic studies raises the awareness of the usefulness of central cancer registry data.

The first example of an epidemiologic study using central cancer registry data comes from New York. Researchers use data collected by the **New York State Cancer Registry** to identify cancer patients who can be interviewed about possible exposures they had before they were diagnosed with cancer. These can be compared to interviews among people without cancer to determine if cancer patients had different exposures. One study of this kind found a possible association between alcohol intake and breast cancer.

Central Cancer Registry Use of Data

◆ Epidemiologic studies (continued)

➤ Example 2: Maine Cancer Registry

- Evaluation of decrease in incidence rate of cervical cancer
- Collaborated with Maine Breast and Cervical Health Program and Maine Behavioral Risk Factor Surveillance System
- Both programs reported an increase in the percentage of adult Maine women having a Pap test
- Results: Pap test screening is critical in the prevention and early detection of cervical cancer

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The next example of an epidemiologic study using central cancer registry data comes from Maine.

Throughout the early and mid 1990s, the incidence rate of cervical cancer in Maine was consistently higher than the national rate. From 1995 through 2000, the **Maine Cancer Registry** (MCR) observed a continuous drop in the incidence of cervical cancer with Maine's incidence ultimately falling below the 2000 national rate of 7.3 per 100,000. The MCR hypothesized that the decline of cervical cancer in the state was largely due to the successful use of Papanicolaou (Pap) testing in detecting pre-malignant changes or early cancer. The MCR reviewed data from the Maine Breast and Cervical Health Program (MBCHP), which began providing no-cost Pap screening tests to eligible Maine women in 1995. This program had noticed an increase in cervical cancer screening from 1995 to 1999. The MCR then collaborated with the Maine Behavioral Risk Factor Surveillance System (MBRFSS) to explore estimated Pap test screening rates among all women in Maine. According to a MBRFSS publication for the period 1994–2002, a significant increase occurred in the percentage of adult Maine women who reported having a Pap test within the past 3 years (89% in 1994 to 92% in 2002).

Just as the incidence rates of cervical cancer in Maine have decreased during the last decade, so too have mortality rates from cervical cancer. This study showed that screening using Pap tests is critical in the prevention and early detection of cervical cancer and that the public health system must continue to educate women and providers; eliminate barriers to screening; and reduce known risk factors, such as prevalence of sexually transmitted diseases and smoking.

Central Cancer Registry Use of Data

◆ Epidemiologic studies (continued)

- Example 3: New Jersey State Cancer Registry
 - Effects of naturally occurring radium in drinking water and the number of cases of osteosarcoma
 - Osteosarcoma rates calculated for populations consuming drinking water containing different levels of radium
 - Radium in drinking water found to be associated with an increase of osteosarcoma in males aged 25 and older
 - Community water systems evaluate drinking water for radium and install treatment systems
 - Homeowners with private wells remove radium with properly maintained water softeners

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Our next example of central cancer registry uses for epidemiologic studies comes from New Jersey. The New Jersey Department of Health and Senior Services developed a study to assess the effects of naturally occurring radium in New Jersey drinking water and the number of cases of osteosarcoma reported to the **New Jersey State Cancer Registry**. Water systems were mapped with characterization of radium exposure levels using recent U.S. geological surveys and surveys by the New Jersey Department of Environmental Protection. Populations using community water systems were estimated by a method involving GIS techniques, water system boundaries, and census data. Osteosarcoma cases were geocoded and assigned to water sources based on residence at the time of diagnosis. Osteosarcoma rates were calculated for populations consuming drinking water containing different levels of radium.

Radium in drinking water was found to be associated with an increase of osteosarcoma in males aged 25 and older. No association was found among females. The study supports the U.S. Environmental Protection Agency's estimated lifetime increase in health risk based on highly exposed occupational and medically exposed cohorts. The full report, *Radium in Drinking Water and the Incidence of Osteosarcoma*, was published by the New Jersey Department of Health and Senior Services. Testing of drinking water now includes 48 to 72 hour tests to capture potential radium exposures. Community water systems are evaluating drinking water for radium and installing treatment systems as needed. Homeowners with private wells can easily remove radium with properly maintained water softeners.

Who Uses CCR Data?

- ◆ Department of Health Services
- ◆ Researchers (public and private)
- ◆ Legislature
- ◆ Other government agencies
- ◆ Media
 - ATSDR's *Principles and Practices Working with the Media*
 - <http://www.atsdr.cdc.gov/risk/riskprimer/media.html>
- ◆ American Cancer Society
- ◆ NAACCR

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We have seen many uses of central cancer registry data and I'm sure you have recognized examples of data usage by the researchers and agencies listed on this slide.

- We have seen how the Department of Health has used central cancer registry data in health event investigations and to evaluate other health department programs.
- We have seen how both public health and private researchers have used central cancer registry data in epidemiologic studies.
- Legislators have used central cancer registry data to identify public health issues that need additional funding to monitor health risks.
- The media can be a primary opportunity for communicating with the public. Therefore, positive relationships with media outlets are crucial. ATSDR identifies several areas of media interest: They are human interest stories, bad news more than good news, people's perspectives, yes or no/safe or unsafe answers, and front-page news stories. ATSDR has also published *Principles and Practices Working with the Media*. It is a concise discussion of how to communicate with the media. This can be found on their website at <http://www.atsdr.cdc.gov/risk/riskprimer/media.html>.
- The American Cancer Society uses central cancer registry data in many ways. ACS researchers frequently collaborate with central cancer registries to conduct special studies. The cancer survivors are identified and selected through state central cancer registry databases. Incidence data in the annual ACS *Cancer Facts and Figures* are collected by the SEER Program and the National Program of Cancer Registries. Another example is the ACS's Behavioral Research Center implementation of a research program to assess the quality of life of cancer survivors.
- The central cancer registries of the SEER Program and the National Program of Cancer Registries, together with the Canadian provincial and territorial central registries, submit data to the North American Association of Central Cancer Registry's annual *Cancer in North America* database and publication. NPCR, SEER and NAACCR work together to publish *United States Cancer Statistics* each year.

Who Uses CCR Data?

- ◆ Cancer Information Service
- ◆ Cancer control agencies
- ◆ Community outreach programs
- ◆ Other programs evaluating health-related issues
- ◆ Pharmaceutical companies developing new drug applications
- ◆ Legal system
- ◆ General public

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These are other agencies that use cancer registry data. Most of these are programs or services within central cancer registries, departments of health, or other government agencies.

Other CCR Uses of Data

◆ Internal CCR Data Use

● CCR data management reports

- Do not provide information about the status of cancer
- Provide information about status and operation of data collection
 - Quantity of work moving through the registry
- Type of reports
 - Simple counts to complicated statistical analysis
 - Prepared with pencil and paper or with sophisticated statistical software
 - Provide descriptive information about the CCR

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Management reports do not provide information about the status of cancer in the population. Rather, these reports are used to provide information about the status and operation of the data collection and surveillance system. Management reports can range from simple counts to complicated statistical analysis. They can be prepared with pencil and paper or be produced with sophisticated statistical software. In their simplest format, the reports can provide descriptive information about the central cancer registry system, such as the quantity of work moving through the registry (counts). More complex reports can compare actual counts against expected values, or cross tabulate one set of values against another. They can include calculations of summary statistics, such as percentages, means, and medians. Displaying management information in charts and graphs for visual impact is very useful. Management information can be used to trigger actions or interventions to improve central cancer registry system response.

Other CCR Uses of Data

- **CCR data management reports** (continued)
 - **NPCR: 2007 standards require CCRs to use management reports**
 - **The North American Association of Central Cancer Registries (NAACCR) -- standards for management reports for several years**
 - **CCRs should produce management reports with a frequency that will facilitate monitoring the operations of the registry**

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•In 2007, the National Program of Cancer Registries or NPCR revised their standards and included a requirement that central cancer registries use management reports to monitor registry functions. The North American Association of Central Cancer Registries (NAACCR) has had standards for management reports for several years. The NAACCR Management Report standards state that central cancer registries should produce management reports with a frequency that will facilitate monitoring the operations of the registry.

Other CCR Uses of Data

- CCR data management reports (continued)
 - Types of management reports
 - Facility-Reporter list
 - Completeness reports
 - Timeliness reports
 - Suspense processing
 - Visual editing
 - Computer editing
 - Linkage and consolidation

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There are many types of management reports. We'll discuss only a few.

- The first type are the **facility-reporter list** and **completeness reports**. The most basic report is of counts, such as counts of case reports by facility by diagnosis year and month, or by month reported.
- **Timeliness reports** can be used by both the CCR and by reporting facilities. For the central cancer registry, this report can contain dates reflecting central cancer registry activity and measuring timely central cancer registry processing, such as intervals after the case is received in the central cancer registry. For facilities, this report can include the intervals reflecting facility activity such as the number and percentage of cases received from the facility, the interval between specified dates such as by date of diagnosis or date of first contact.
- **Suspense processing reports** provide the status of cases in process. These reports provide information on the length of processing time.
- **Visual editing reports** contain the percent of cases with any error compared to those with no errors. They can also contain the percent of cases requiring queries to the reporting facility, as well as error rates by data item, facility, and over time.
- **Computer Editing reports** contain the average number of errors per case, number of edits triggered, and number of errors per edit. This can be tabulated by batch, facility, software vendor, or for a specific time period.
- **Linkage and Consolidation reports** contain the total number of case reports, patients, and tumors that result from consolidation activities. They can also contain the ratio of case reports to tumors and the ratio of tumors to patients.

Other CCR Uses of Data

- **Facility management reports**
 - CCR depends on reporters that are motivated to produce timely and complete data
 - Facility reports
 - Close quality improvement loop
 - Improve timeliness and accuracy of data
 - Provided as a service to local facilities
 - Types of facility reports
 - Inconsistency reports
 - Computer edits reports
 - Case consolidation reports

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The central cancer registry surveillance system works best when those who are preparing and submitting data are motivated to produce the most timely and complete data possible. Even when cancer reporting is mandated by law, the central cancer registry relies heavily on the voluntary cooperation and goodwill of its reporting facilities for smooth operation and quality data. Providing data to the facilities so that the data flow becomes two-way is an effective way to build cooperation.

Facility management reports often serve the purpose of closing the quality improvement loop, and improving timeliness and accuracy of data. Other reports can be provided as a service to local facilities so that the hospitals are customers and users of the data as well as suppliers.

Inconsistency reports, computer edits, and information from case merges or consolidation are types of reports that can be provided to facilities to improve data quality. Reports from computer and visual edits can be used in the central cancer registry to correct errors in the data, but providing reports back to the reporting facilities allows the registrars to learn from their mistakes, to prevent future errors, and to make future central cancer registry procedures more efficient. It also allows the registrars an opportunity to correct any errors or assumptions the central cancer registry has made. Sometimes the central cancer registry can introduce inaccuracies into the data during their error correction process, and the hospital registrar can review and correct the central cancer registry's mistakes.

Other CCR Uses of Data

- **Other facility reports**
 - **Follow up assistance**
 - Death clearance
 - Information obtained from other sources
 - **Shared follow-up on living patients**
 - Subsequent admissions at other facilities
 - Other linkage: motor vehicles, voter registration

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The central cancer registry can be of great value to hospital registries by providing follow-up information on registered cases and comparison data that the hospitals can use in their own reports. Both examples help the facility meet requirements of the American College of Surgeons Commission on Cancer (COC).

To provide assistance in follow-up, the central cancer registry may be able to share results of death clearance with reporting facilities by providing them with information on the death of a registered patient. In some states, release of information may be restricted by the Vital Statistics office, so the central cancer registry must ascertain what information they are authorized to re-release to facilities. At a minimum, the central cancer registry should be able to provide the fact that the death has occurred and the date of death.

Depending on local information sharing regulations, it may also be possible to share follow-up information obtained from one source with another source that has also reported the case. This benefits the facilities by reducing the number of follow-up inquiries they must send out. Sharing of follow-up information must be approached carefully and discussed with all facilities concerned, as well as legal advisors of the central cancer registry, since release of information may be legally restricted. It may require that participating hospitals sign agreements that specifically allow limited sharing of follow-up information with other facilities. It may be time consuming initially to implement this, but the goodwill gained as a result will be invaluable.

The central cancer registry may also obtain follow-up from linkages it performs with other databases, such as the Motor Vehicle Department or voter registration records confirming that a patient is alive. It may also be possible to share this information with the reporting facility.

Other CCR Uses of Data

- **Other facility reports** (continued)
 - **Comparison data**
 - Local area or entire state
 - Routinely or on request
 - **Type of data**
 - Site/stage distribution
 - Special tabulations
 - County/parish
 - Zip code
 - Census tract
 - **Timeliness: 1 2 years out of sync**
 - **Confidentiality concerns**

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The central cancer registry can provide valuable comparison data to facilities, such as site and stage distributions of cases for a local area or the entire state, either routinely or on request.

Often administrators want comparison data. How does your hospital compare to another facility? How does your area compare to the rest of the state?

However, central cancer registries need to prepare these reports carefully. Expertise is required to provide the most appropriate comparison data. The reports should be prepared or reviewed by someone with statistical and epidemiological knowledge. Care must be taken to preserve the confidentiality not only of individual patients, but also the individual hospitals and physicians. Hospitals receiving the data should be cautioned regarding interpretation of the results. For example, the statewide data may be 1 or 2 years older than the hospital's data, so comparisons might be from different years.

Other CCR Uses of Data

- **Facility Reports**
 - **Sharing Mechanism**
 - **Electronic download**
 - Accession number, medical record, sequence number
 - **Paper list**
 - **Copies of death certificates**
 - **Confidential patient information should be transmitted using a secure method**

Full report: *Cancer Registry Management Reports* on
NPCR Website:
<http://www.cdc.gov/cancer/npcr/registry/management/>

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Data or reports can be provided to reporters in different media. Paper reports can be mailed and reports can be e-mailed or accessed through the Internet. When follow-up data on individual cases are downloaded to facilities, it is essential that the data be identified accurately by numbers that the hospital uses in its database, such as the hospital's accession number and medical record number.

Copies of death certificates may be useful to hospitals, but their distribution may be prohibited by Vital Statistics, and the central cancer registry may not have enough staff to produce paper copies.

Confidential patient information should be transmitted using a secure method.

A full report titled *Cancer Registry Management Reports* can be found on the NPCR Web site at the address on the slide.

Marketing With CCR Data

◆ CCR support

- Financial support
- Political support
- Infrastructure support
- Other types of support

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Central cancer registries cannot operate without resources, and resources are tied to various levels of support. The most obvious types of support for central cancer registries come from political and financial sources which are closely related.

- **Financial support** may be from state, national, or other sources. However, in today's economy there is always fierce competition for these funds. Central cancer registries need to determine what they can do to ensure that those making funding decisions see the importance of continuing to fund cancer surveillance activities.
- **Political support** comes from both the state and national levels. Central cancer registries should determine which agencies and legislative officials might be interested in central cancer registries for personal reasons. These individuals or agencies can be instrumental in obtaining support for the central cancer registry.
- **Infrastructure support** includes human resources (personnel) and facility support such as space, equipment, supplies.
- **Other types of support** come from the community, medical, cancer advocacy groups, patients, and the general public.

Marketing With CCR Data

- ◆ Develop a marketing plan
 - Define the CCR image
 - Demonstrate CCR's usefulness
 - Public health
 - Health promotion
 - Prevention programs
 - Other cancer control activities
 - Promotion should be ongoing
 - Plan for increased data requests

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Central cancer registries should not leave something as critical as marketing the registry to chance. They need to develop a marketing plan.

The first step is to **define the image** that the central cancer registry wants to present. The image should be clear, simple, consistent, and goal oriented. The central registry should make a good and lasting impression.

The next step in developing a central cancer registry marketing plan is to identify the market for data and other services. The central cancer registry will want to demonstrate the central cancer registry's **usefulness** to public health, health promotion, prevention programs, and other cancer control activities. The central cancer registry should also identify specific audiences to direct marketing activities.

Central cancer registry promotion should be **ongoing**. Possibilities for marketing activities include newsletters, brochures, websites, presentations, press releases, both feature or special-interest articles, statistical monographs, and medical or research-oriented reports. We will discuss some of these in detail later in the presentation.

After the marketing plan has been developed, the central cancer registry needs to **plan ahead** for the potential of increased requests for data. The amount of time needed to complete and respond to requests for data should be determined because it is important to answer all requests as quickly as possible to make a positive impression of the central cancer registry's usefulness.

Marketing With CCR Data

◆ CCR promotion

● Press release examples

- Arkansas: First time data included in United States Cancer Statistics
- Colorado: Cancer cluster investigation finds no evidence of linkage of adverse health effects
- Oklahoma Central Cancer Registry receives NAACCR Gold award
- Funding received for project to develop cancer maps for Pennsylvania



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Press releases are a good way to present positive information on central cancer registries in the newspaper. Central cancer registries can work with their external communications department to prepare these releases. There is no guarantee that the news services will pick up on the release, but there is always a possibility. The following are some examples of CCR press releases.

- *Arkansas Included for First Time in Cancer Report by The Centers for Disease Control and Prevention* Information Provided by Arkansas Department of Health (ADH); Arkansas Central Cancer Registry
- *Lookout Mountain Study Updated By State Health Department:* DENVER. There is no conclusive evidence of any linkage of adverse health effects among Lookout Mountain residents to the high-powered broadcast antennas and transmitter towers located in the area west of Denver, the Colorado Department of Public Health and Environment reported Thursday in an update of a 1999 study. The new study, in addition to considering new population figures, reviewed cancer statistics compiled by the **Colorado Central Cancer Registry** for the Lookout Mountain area for the period of 1998–2002.
- *Oklahoma Central Cancer Registry earns gold award* Posted: 5/19/2006. The North American Association of Central Cancer Registries has awarded the **Oklahoma Central Cancer Registry** with NAACCR's Gold Standard Award.
- *New Project Will Develop Cancer Maps for Pennsylvania:* Press Release - December 16, 2003 Hershey, Pa. A 3-year, \$736,000 grant from the Association of American Medical Colleges and Centers for Disease Control and Prevention (CDC) will allow Penn State Cancer Institute to develop cancer maps to identify Pennsylvania communities with particularly high rates of colorectal and prostate cancer. Based on data from the **Pennsylvania Central Cancer Registry** of the state Department of Health, the extent of the burden of colorectal and prostate cancers varies by geographic region.

Marketing With CCR Data

◆ CCR promotion (continued)

● CCR publication examples

- Nebraska State Cancer Registry: *Nebraska Medical Association*
 - Number of cases submitted to the CCR with unknown race
- South Carolina Central Cancer Registry: *Cancer Control*, 2006
 - *The effect of physician permission versus notification on research recruitment through registries*
- Wisconsin Cancer Reporting System: *Wisconsin Medical Society Journal*
 - *Racial/Ethnic Data Reminder System: Report Racial/Ethnic Data to Wisconsin Cancer Reporting System*

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Publication in medical journals is a good way to demonstrate the central cancer registry's usefulness to others in the medical profession, especially to physicians. The following are examples of central cancer registries that have used this media.

- Nebraska State Cancer Registry submitted an article to the *Nebraska Medical Association* on the number of cases submitted to the central cancer registry with unknown race.
- *The effect of physician permission versus notification on research recruitment through registries* was published by the South Carolina Central Cancer Registry in *Cancer Control* in 2006.
- Wisconsin Cancer Reporting System published article in *Wisconsin Medical Society Journal*, *Racial/Ethnic Data Reminder System: Report Racial/Ethnic Data to Wisconsin Cancer Reporting System*.

Marketing With CCR Data

- ◆ CCR promotion (continued)
- CCR publication examples
 - CCR collaboration with other researchers
 - *Research Recruitment Through U.S. Central Cancer Registries: Balancing Privacy and Scientific Issues*
 - in *American Journal of Public Health*, 2006
 - Authors from
 - University of North Carolina School of Public Health
 - Veterans Affairs Medical Center
 - University of North Carolina Department of Medicine and Center for Gastrointestinal Biology and Disease

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Central cancer registries can collaborate with other researchers to present central cancer registry information.

- *Research Recruitment Through US Central Cancer Registries: Balancing Privacy and Scientific Issues*, American Journal of Public Health, November 2006. The authors are from the Department of Health Policy and Administration, University of North Carolina School of Public Health, Chapel Hill, Center for Health Services Research in Primary Care, Veterans Affairs Medical Center, Durham, NC and the Department of Medicine and the Center for Gastrointestinal Biology and Disease, University of North Carolina, Chapel Hill.

Marketing With CCR Data

- ◆ CCR promotion (continued)
 - Newsletter examples
 - Arkansas Department of Health
 - Central Cancer Registry Updates
 - Minnesota Cancer Surveillance System
 - Department of Health Disease Control Newsletter
 - Regularly submits short articles
 - Florida Cancer Data System
 - The Register
 - Article on FCDS





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Newsletters are another way to reach the medical community. These newsletters can represent a variety of audiences including physicians and other department of health organizations. The following are examples of central cancer registries publishing information in various newsletters.

- The **Arkansas Department of Health** publishes the Arkansas Central Cancer Registry Update. One of the articles in this newsletter discusses the fact that AR CCR is receiving records with missing primary sites, date of diagnosis, histology and behavior codes.
- The **Minnesota Cancer Surveillance System** regularly submits short articles to Department of Health Disease Control Newsletter which is circulated to almost all physicians in the state.
- The **Register** is a joint project of the Sylvester Comprehensive Cancer Center and the Florida Department of Health Division of Cancer Prevention and Control. An article on the Florida Cancer Data System was published in Volume 27, 2005.

Marketing With CCR Data

- **Newsletter examples** (continued)
 - **South Carolina Central Cancer Registry**
 - Savannah River Region Health Information System Newsletter
 - Implementation of CCR
 - **North Dakota Cancer Registry**
 - North Dakota Department of Health Newsletter
 - Initiation of the CCR and adoption of mandatory reporting
 - **Kentucky Cancer Registry**
 - Kentucky Epidemiologic Notes and Reports
 - Report on the CCR activities

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- The **SRRHIS Newsletter** is published by the Savannah River Region Health Information System at the Medical University of South Carolina. In October 1993, there was an article announcing the implementation of the **South Carolina Central Cancer Registry**, which began: “Many years of planning, persistent committee activity, and recent financial support from CDC, have culminated in the establishment of the South Carolina Central Cancer Registry.”
- **North Dakota Department of Health Newsletter** published an article in the Spring 1999 issue describing the initiation of the **North Dakota Cancer Registry** and adoption of mandatory reporting of all invasive and in situ cancer.
- **Kentucky Epidemiologic Notes and Reports.** A report on the **Kentucky Cancer Registry** activities was published in the newsletter for the Cabinet for Health and Family Services Department for Public Health, Division of Epidemiology and Health Planning, in February 2006.

Marketing With CCR Data

- **Flyers and brochures**
 - **Information about the CCR**
 - Posted on websites
 - Included with initial contacts to new reporters
 - Provided to county health departments
 - **Mississippi Central Cancer Registry**
 - Received Hospital Association award for CCR brochure
 - **Wisconsin Cancer Reporting System**
 - Collaborated with Wisconsin Cancer Council
 - Developed physician-directed flyers and brochures on importance of collecting and reporting data on race and ethnicity



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Many central cancer registries have informational brochures about the central cancer registry. These are frequently posted on their websites and distributed in a variety of ways. They are frequently included with initial contacts to new cancer data reporters, such as physicians and other non-hospital facilities. They can also be provided to county health departments.

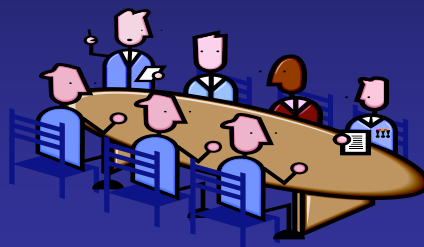
In 2001, the Mississippi Hospital Association Maggie Award for brochure design was given to the Department of Health Central Cancer Registry.

The Wisconsin Cancer Reporting System collaborated with the Wisconsin Cancer Council to develop flyers and brochures geared toward physicians highlighting the importance of collecting and reporting data on race and ethnicity.

Marketing With CCR Data

- **Advisory Boards**

- Play a major role in marketing CCR
- Membership often includes representatives from marketing plan target audiences
- Members can act as advocates for CCR support



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Advisory or Steering Committees can play a major role in marketing the central cancer registry.

Membership on the Advisory Committee often includes representatives from many of the target audiences identified in the central cancer registry's marketing plan.

These members can also act as advocates for central cancer registry support.

Marketing With CCR Data

● Advisory Boards (continued)

➤ Examples

— Texas Cancer Registry (TCR)

- Texas Cancer Data Work Group Funding/Rules subcommittee
- Provides support to secure adequate funding of the TCR
- Identifies alternative funding sources
- Provides advice on laws, regulations and policies when needed

— Ohio Cancer Registry

- Ohio Cancer Incidence Surveillance System Advisory Board
- Statutory requirement for annual report to the Finance Committee Chairpersons of both houses of the Ohio General Assembly

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The Texas Cancer Data Work Group is a committee that supports and advises the Texas Cancer Registry. The Funding/Rules subcommittee provides support to secure adequate funding of the TCR and seek and identify alternative and supplementary funding sources. This subcommittee also has as its responsibility providing advice on laws, regulations and policies when needed.

By statutory requirement, the Ohio Cancer Incidence Surveillance System Advisory Board must report annually on the status and progress of the cancer surveillance system to the Finance Committee Chairpersons of both houses of the Ohio General Assembly.

Summary

- ◆ **Many types of registries**
 - Collect data for different reasons
 - Use data in different ways
- ◆ **Data usage is a major activity for statewide CCRs**
 - Users of statewide CCR data
- ◆ **All types of registries can use their data to market the registry.**

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In this presentation we have reviewed the many types of facility and central cancer registries and discussed the different ways they collect and use their data.

We have looked at many of the ways statewide central cancer registries use their data, as well as who uses their data.

We have also reviewed how facility and central cancer registry data can be used to market the cancer registry.

This completes the second and final part of this presentation on cancer as a reportable disease. Thank you for your attention.

The findings and conclusions in this presentation are those of the authors and do not necessarily represent the views of the Centers for Disease Control and Prevention.



**For information about CDC's
Cancer Prevention and Control Programs
and the
National Program of Cancer Registries**

**Please visit
www.cdc.gov/cancer/npcr**

